

# The ‘Yin and Yang’ of UNOS

*A personal retrospective on UNOS’ first two decades*

BY WALTER GRAHAM

**I**n the late summer of 1986, I was the vice president of health care and information technology for a Washington, D.C., consulting firm. Gene Pierce, the UNOS founder, called our firm for assistance.



Walter Graham

UNOS had submitted the sole bid for the initial OPTN contract, but its bid did not meet government specifications.

Pierce wanted us to help rewrite the bid proposal. We agreed, but on the condition that we could be a subcontractor to help implement the computer system.

One month later, the Department of Health and Human Services (HHS) awarded UNOS the contract to implement the Organ Procurement and Transplantation Network (OPTN). I

led the consulting team and in 1987 joined UNOS as a full-time employee. On May 4, 1987, following several former employees who had transferred to UNOS from its predecessor organization, the SouthEastern Organ Procurement Foundation (SEOPF), I became UNOS’ 15th employee.

As assistant executive director responsible for all operations, I was also named project director for the OPTN contract. Pierce turned to me to build an operating infrastructure for UNOS, including hiring and managing staff. From that handful of employees, we now have grown to a staff of 300.

Over the past 21 years, I have witnessed UNOS grow from an emerging operation to the extensive, maturing organization it is today. This article briefly recounts that evolution, dividing UNOS history into two eras.

Due to space limitations, it is impossible to give credit to all individuals who have helped construct this unique American health-care institution. But I would be remiss if I did not give enormous credit to Gene Pierce for his vision and creativity—most of the basic organizational structure remains as he first developed it. The brilliance of his plan for UNOS is evident today.

## UNOS’ UNIQUE CHARACTER

UNOS is unlike any other organization I have encountered, especially in its role as the OPTN. A hybrid organization, UNOS is a not-for-profit membership corporation that qualifies as a charity under IRS rules as a scientific and educational organization.

In its capacity as the OPTN, UNOS and its members determine—with government oversight provided by the Health



A few of UNOS’ first employees. At center is founder/executive director, Gene Pierce. Around the table, from left, are Pat Daily, John Persons, the author and Cindy Sommers.

Resources and Services Administration (HRSA)—the policies that guide organ transplantation in this country.

Because of the organ shortage, organ transplantation necessarily entails mutual interdependence of practice among those providing organ transplantation to patients with end-stage organ failure. Transplant surgeons and physicians participate in managing each other’s patients, since decisions made about one’s own patients impact patients of others directly, unlike anywhere else in medicine.

UNOS’ governance system recognizes this mutuality. It is unusual in that it brings together the providers of the service—surgeons, physicians, coordinators, histocompatibility experts and OPO representatives—with the beneficiaries of the service—transplant candidates and recipients. A third and very important group, living donors and deceased-donor family members, act as the public conscience in this extraordinary undertaking.

The creation of policy based upon consensus among practitioners with a mutuality of interdependence and other constituent groups with widely divergent interests gives UNOS and the OPTN a unique character.

UNOS is both a membership organization, serving its members, and a government contractor, serving HRSA, the agency that awards its contract. Those two masters are not always perfectly aligned in the direction they seek for UNOS and the OPTN—hence the “yin and yang” of UNOS.

From the beginning, however, we on the UNOS staff have understood that although we provide services for the membership and the government, UNOS’ ultimate reason for existing is for the patients being served by the entire system. That understanding has guided our efforts over the years and continues today.

## DEVELOPING ERA (1986–2000)

During its formative years, UNOS implemented and operated the OPTN as part of its ongoing operations as a private and completely voluntary membership network. When the 1984 National Organ Transplant Act (NOTA) called for the formation of a national transplant network, Congress envisioned a group like UNOS, and as an example of what they were looking for referred to UNOS by name in the background documents leading up to the new law.

OPOs, transplant centers and histocompatibility laboratories initially joined UNOS because they saw the benefit of a single national organization to coordinate transplantation.

The Omnibus Reconciliation Act of 1987 added a provision to the Social Security Act, however, that altered the original vision of the OPTN. Now, in order for OPOs and transplant hospitals to be eligible for Medicare and Medicaid funds, the new provision required them “to belong to and abide by the rules and requirements of the OPTN.”

If OPOs and transplant hospitals did not join the OPTN and abide by its rules and requirements, the entire institution, not just the transplant programs, would be ineligible to be a Medicare/Medicaid provider. UNOS was no longer a voluntary organization in the truest sense.

A response came in 1989 from the Health Care Financing Administration, or HCFA (now the Centers for Medicare and Medicaid Services, or CMS). HCFA announced in the Federal Register that it would not enforce the new Social Security Act requirement until HHS had formally decided what “abiding by the rules and requirements of the OPTN” meant—which would entail publication of that decision in a “Final Rule.”

In the meantime, the OPTN would remain a voluntary network.

From 1989 on, the OPTN contract awarded to UNOS by HRSA called for a network in which all the policies were considered to be “voluntary guidance,” not enforceable by the OPTN.

## EMPHASIZING CONSENSUS

During this era, UNOS developed its approach to operating the OPTN. Because compliance with OPTN policies was voluntary, UNOS developed its policies on the basis of consensus. The major emphases included organ allocation and establishment of requirements for membership within the OPTN. Also included in UNOS’ voluntary approach were policies on OPTN members listing patients for transplantation and receiving deceased donor organs for these patients.

UNOS leadership believed that if they could achieve broad consensus among members regarding a policy, the members would be more likely to follow it. This reliance on consensus led to an emphasis on inclusion, participation, democratic representation and recognition of the unique mutual interdependence of practice inherent in organ sharing and transplantation.

UNOS continues to adhere to these principles while constantly seeking to improve how we execute them. From my personal perspective, two important things occurred in 1995.



An early iteration of the Organ Center. On the left is Jim Creger, who worked at the Organ Center for 21 years, with organ placement specialist Carolyn Harris. Creger began his transplant career in 1982 at the South-Eastern Organ Procurement Foundation.

First, I became the executive director of UNOS when my predecessor, Gene Pierce, retired. Second, HHS published proposed federal regulations for governance of the OPTN. The regulations were required due to HHS’ understanding of the Social Security Act’s new provision regarding OPOs and transplant centers complying with OPTN rules and requirements.

In 2000, after extensive public comment, public hearings and discussions with the community, HHS issued the OPTN Final Rule, which established the operating parameters for the OPTN. This event ushered in a new era in UNOS history.

*Editor’s Note: In part 2 of his retrospective, Graham describes UNOS’ implementation of the Final Rule and anticipates UNOS’ future directions.*

Walter Graham, J.D., is executive director of UNOS.

## BOARD NOMINATION FORMS NOW ONLINE

Do you know someone with expertise in process improvement and increasing the organ supply and who represents an organization with a solid record of compliance with OPTN policies?

The OPTN/UNOS nominating committee is soliciting recommendations for **vice president/president-elect, treasurer, one minority transplant representative and patient and donor affairs representatives** who represent the interests of recipients, candidates, living donors, family members and voluntary health organizations.

The “candidate biography form” is available at [optn.org](http://optn.org) and [unos.org](http://unos.org). The form should be filled out **by the candidate** and e-mailed no later than **Fri., Aug. 29**, to Karen Rice at [ricekm@unos.org](mailto:ricekm@unos.org). E-mail is preferred, but faxes also are accepted at (804) 782-4816.

The OPTN/UNOS nominating committee will present the slate of nominees for approval to the OPTN/UNOS board at its November meeting.